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SURVEY OF INFORMAL CARERS, GREAT BRITAIN(1)

Report submitted by the Office of Population Censuses and Surveys[1/]

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I am presenting a paper on informal care at a conference on women because caring is typically thought of as women's work. However, as will be discussed later, one of the most surprising and controversial findings of our survey was that a substantial proportion of men were involved in caring.

1. Introduction

At the request of the Department of Health, a series of questions was included in the 1985 General Household Survey to identify people looking after a disabled or elderly person. The main aim of the questions was to provide estimates of the numbers of informal carers in Great Britain and to describe their characteristics. This information was needed to help plan services for carers and to provide a national perspective on the results of more detailed local studies.

The General Household Survey (GHS) is a multipurpose continuous survey based on a representative sample of the general population living in private households in Great Britain. Approximately 10,000 households are included each year and interviews are carried out with all adults (persons aged 16 or over) in the sampled households. The questions on informal care were addressed to about 18,500 adults living in households sampled for the 1985 survey. Those identified as carers were asked about the number of disabled or elderly people they looked after (referred to as 'dependants' in this paper). Details were then collected about each dependant and the nature of care provided. Information was obtained for approximately 77% of the total eligible sample of adults.

There has been relatively little research into informal care and this study was the first national survey of carers to be carried out in Great Britain. It was therefore a very exploratory project and intended as a base on which future work in this area could build.

This paper describes two aspects of the research which presented problems of measurement: first, the definition of informal care and identification of carers and second, the assessment of the burden of care.

2. Definition of informal care

There is no widely accepted definition of informal care and few studies have included questions to identify carers. It was therefore necessary to develop a definition for the survey. Our aim was to design questions which would identify carers looking after someone living either in the carer's home or in another private household and which would include those providing relatively small amounts of care as well as those with heavy demands upon them.

The concept of caring was first established in the interview in relation to people caring for a dependant living in the same household as the carer. It was necessary to distinguish between help normally given by one household member to another and the special help needed by people who are disabled. For this purpose, the introduction to the questions included a reference to 'extra family responsibilities'. For those caring for someone outside the household, we wanted to ensure that people providing relatively small amounts of help were included (for example, people who collected shopping or library books for a disabled person). The question to identify this group therefore referred to 'providing a regular service or help' for the dependant. The questions were:

Q1. Some people have extra family responsibilities because they look after someone who is sick, handicapped or elderly.

May I check, is there anyone living with you who is sick, handicapped or elderly whom you look after or give special help to (for example, a sick or handicapped or elderly relative/husband/wife/child/friend, etc) (SPECIFY ALL HOUSEHOLD MEMBERS)?

Q2. And how about people not living with you, do you provide some regular service or help for any sick, handicapped or elderly relative, friend or neighbour not living with you?

The questions were tested in a pilot study before being included in the main survey.

The absence of a strictly objective definition of a 'carer' meant that, in the last resort, we had to rely on the informant's subjective opinion as to whether or not he/she was a carer. Although this was unavoidable, it was recognised that the screen questions might not identify all carers. The pilot test suggested that there might be a few informants apparently carrying out informal care but who did not consider the caring role to be an 'extra family responsibility'. The interviewer was therefore asked to note any cases in which an informant had answered the screen question negatively but the interviewer was confident that he/she was providing a substantial amount of care. This check was possible only for carers looking after someone living with them, as in this case the interviewer was aware of the dependant's household situation. However, such omissions were unlikely to occur among carers with dependants outside the household as the question to identify these carers was phrased differently. Of 18,565 adults who responded to Q1 above, there were 56 people (0.3%), mainly people caring for a spouse, whom the interviewers considered to be carers but who did not identify themselves as such. These cases were excluded from the analysis. Their exclusion makes no difference to the overall proportion caring or to the proportion caring for someone in the household.

The interviewers were also asked to note any situations in which they felt that informants had incorrectly identified themselves as carers. No such cases were reported.

Reports from the field staff and the small number of apparent carers who did not identify themselves as such suggest that the questions were reasonably successful at identifying people who had fairly heavy demands upon them, that is, those whose caring role was evident from interviews with all adult members of the household. It is more difficult to assess how reliably we identified those with lighter loads. Intuitively, it seems likely that there would be some such carers who would not consider that the help they gave was worth mentioning. However, the results show that many of those with relatively light loads were included and that, as would be expected, they formed a relatively high proportion of the total sample of carers. Over one third of the carers identified were devoting less than 5 hours per week to caring.

Other approaches might have been used to identify carers although it is difficult to envisage a completely objective definition. For example, one could ask a series of questions checking whether or not people carried out various caring tasks. But this would still have involved subjective judgement in distinguishing between tasks normally carried out

for another household member and those performed because of disability. What is regarded as 'normal' may depend, for example, on the age or sex of the person being looked after.

The importance of using an objective definition to identify carers will depend to a large extent on the aims of the research. The purpose of this study was to provide information to help the Health Department estimate the demand for services. It is likely that carers who see their role as a normal family responsibility will make fewer demands than those who consider it to be extra duty. In this sense, a person's view about whether or not he/she is a carer may be a better indicator of the demand for services than a more objective identification.

The main estimates from the survey are shown in Table 1. Fourteen per cent of people aged 16 or over said that they were looking after, or providing some regular service for, someone who was sick, handicapped or elderly. Although the public image of carers is of a predominantly female group, the proportion of women caring (15%) was not markedly higher than that of men (12%). Men and women were equally likely to care for someone living with them (4% for both sexes) but women were more likely to care for people outside the household, 11% compared with 8% of men.

While it is surprising that there is not a greater difference between the sexes in the overall proportion caring, we have no reason to believe that the figure for women is an under-estimate. The group of apparent carers who did not identify themselves contained similar numbers of men and women and our estimates were comparable to those obtained in a local study carried out at around the same time. But, since there are more women that men in the total population of Great Britain, it is true that the number of women caring is considerably greater than that of men. The survey figures represent about 6 million carers overall in Great Britain, 3.5 million women and 2.5 million men. The fact that carers are more likely to be women than men may be one reason for the popular idea that women are more likely than men to be carers. As will be discussed later, there were some differences between men and women in the extent to which they shouldered the burden of care.

3. Measuring the burden of care

Within the total sample of carers, the nature of care provided covered a wide spectrum ranging, for example, from taking the dependant out once a week to almost continuous care. The Department of Health was particularly interested in carers who had heavy demands upon them. The following measures of the burden of care were included in the study in order to distinguish this group:

1. Whether the dependant lived in the same household as the carer.

2. Number of hours devoted to caring.

3. Whether the carer was the main carer for the dependant.

4. Number of dependants cared for.

5. Number of years spent caring for the dependant.

6. Kinds of help given.

7. Support received from other family members or friends and from the professional and voluntary services.

8. Opportunities for taking time off from caring.

9. Other responsibilities/problems, for example, dependent children, paid job, health problems.

The survey did not attempt to explore people's attitudes to caring or its physical, social and financial consequences. These aspects of caring were being covered in smaller scale studies and there was insufficient time available in the GHS interview for the kind of detailed questioning they would require.

The first three measures listed above were our main indicators of the burden of care. Caring for someone in the household was expected to involve a greater commitment for the carer and proved to be closely related to other measures indicating a heavy burden of care. This measure was straightforward. The other two, the time devoted to caring and whether the person was the main carer for the dependant, were more problematic. The following sections describe the difficulties in collecting this information and the inter-relationships between the three main measures of the burden of care.

3.1 Time spent on caring activities

The main difficulty in assessing the time devoted to caring occurred among people giving rather intangible forms of help, for example, being in attendance in case help should be needed, keeping an eye on the dependant and being 'on call' while sleeping. We decided that caring which required the carer's presence during waking hours, even if he or she was not specifically looking after the dependant, should be counted because the need to be in attendance would restrict the carer's activities. Time spent 'on call' while sleeping was excluded because it was very difficult to define precisely and we thought that there would be a lot of variation in how it was interpreted. We are aware that this could be a considerable burden for some carers. However, it is quite likely that such carers would also be spending a substantial amount of time caring during the day so that they would be classified into the 'heavy burden' group on this basis.

For carers giving more specific types of help and those with dependants outside the household, assessing the time spent caring was usually more straightforward, the only special instruction to interviewers being to include travelling time to dependants outside the household.

The pilot test showed that people devoting long hours to caring found it very difficult to calculate the time they spent. To simplify the task, informants were asked to give banded estimates, very broad bands being used for those with long hours. This information was sufficiently detailed for our purposes as our main interest was in dividing the sample into broad subgroups. The

interviewers were briefed to help informants to calculate their hours, if necessary, by going through what happened on each day of the week. Although this was quite time consuming, the results were very encouraging, useable information being obtained for 99% of carers.

Figure 1 shows the close relationship between the time devoted to caring and the first indicator of the burden of care, whether or not the dependant lived in the same household as the carer. Nearly one half of carers whose dependants lived with them were devoting at least 50 hours per week to caring and less than one quarter were spending under 10 hours. Among those with dependants outside the household, about three-quarters were devoting under 10 hours per week to caring. One might consider a commitment of 20 or more hours per week to caring to represent a substantial burden for the carer. Such a commitment was made by about one quarter of carers, representing approximately 1.4 million adults in Great Britain.

3.2 Main carers

Our third measure of the intensity of care was whether the carer was the main carer for the dependant. 'Main carers' were defined as people who were the sole carers of a dependant or who spent more time than anyone else on the care of the dependant. We feel that this is not an entirely satisfactory definition of a 'main carer' in that time spent on caring does not necessarily distinguish adequately the degree of responsibility taken for the welfare of the dependant. Ideally we wanted to establish who took the main responsibility for organising activities, taking decisions, explaining to others what was needed, ensuring that there was supervision, dealing with an emergency and so on. Taking ultimate responsibility for the dependant is likely to be a considerable burden and involves a much greater commitment than merely spending time with the dependant. If the study should be repeated, we would aim to build in these more intangible elements of responsibility.

As Figure 2 shows, nearly one quarter (23%) of carers reported that no-one else helped to look after the dependant. A further 30% said that they received help but spent more time than anyone else on the dependant ('sole main carers') and 11% spent the same amount of time as someone else ('joint main carers'). Together, these groups (referred to as 'main carers') represent two thirds of all carers, which is equivalent to approximately 3.7 million adults in Great Britain. Among those caring for someone in the household, the vast majority were main carers (82%), including a high proportion, 42%, who were coping singlehandedly. Of those with dependants outside the household, 57% were main carers including only 15% with no other help.

As would be expected, main carers tended to devote considerably more time to caring than secondary carers and this was true irrespective of whether or not the dependant was in the household (Table 2). The Table also shows that secondary carers looking after someone in the household tended to devote longer hours to caring than main carers with a dependant living elsewhere. This may reflect the severity of the informant's disability in that severely disabled people who do not have a carer living with them are likely to require institutional care.

Figure 3 illustrates the degree of overlap in the groups with the heaviest burden, as indicated by the three measures discussed. The right hand chart shows that 25% of all carers were spending 20 or more hours per week on caring activities and, as would be expected, the vast majority of these were the main carers of a dependant. The left hand chart shows that the group caring for someone living with them was almost entirely composed of people spending at least 20 hours per week caring or people devoting fewer hours but who were main carers, that is, the lined and/or shaded areas on the left hand chart.

3.3 Other measures of the burden of care

There were a few difficulties with the other measures of the burden of care used in the survey, although most were straightforward. As noted earlier, there are some problems with obtaining information about the kind of help given by carers because of the need to distinguish between help normally given by one family member to another and that given to someone because of disability. For example, help with personal care is normally given to young children and some domestic tasks may be carried out by one person for the rest of the family. The question specified that the help should be 'over and above what would normally be done for the dependant' but it was sometimes difficult for the carer to make this distinction.

Table 3 shows the kinds of help carers gave to their dependants analysed by whether or not the dependant lived with the carer. The first 3 items, help with personal care, giving medication and physical help, involve some degree of intimacy between carer and dependant. These kinds of help were each given by about one half of those caring for someone living with them.

A surprisingly high proportion, 20%, of carers looked after more than one person. These were mainly people caring for both parents or for a relative and a friend. In some cases, having two or more dependants would substantially increase the burden of care but, in others, it might not. For example, cooking or shopping for two elderly parents would probably involve the same amount of effort as doing these tasks for one parent. On the other hand, caring for two dependants who lived some distance apart would probably be a considerable burden. Thus quite detailed information is needed to interpret this measure.

4. Differences between men and women

It was noted earlier that the overall proportion of women caring was not very much higher than that of men (15% and 12% respectively). However, comparisons on the measures discussed above show that women tended to carry the heavier burden of care, as is illustrated in the following analyses.

Figure 4 shows that, among carers looking after someone living with them, 51% of women compared with 39% of men were devoting at least 50 hours per week to caring. Similarly, among those with dependants outside the household, 32% of women compared with 22% of men spent at least 10 hours per week.

Women were also more likely than men to carry the main responsibility for the care of the dependant, either alone or with secondary support (Figure 5). Overall, 59% of women compared with 45% of men were in this position.

There were also differences between men and women in the kind of care given (Table 4). Women were more likely than men to help their dependants with personal care and to give general supervision while men were more likely to take their dependants out.

The group of women who tended to have the heaviest burden of care were single women aged 45 to 64 (Figure 6). In this age-group single women were more likely than ever-married women to be caring for someone living with them (15% and 6%) and more likely than single men to be main carers (22% and 12%). The proportions spending at least twenty hours per week caring for a dependant were also higher among single women aged 45 to 64 (13%) than among single men (6%) or ever-married women (6%) in this age-group. In other age-groups, however, there was no significant difference between single men and women or between single and ever-married women in any of these respects. These findings lend some support to the commonly held view that the caring role falls disproportionately on single women but the disparity is only evident in later middle age. It must be remembered too that the numbers involved are very small: single female carers represent only 11% of all female carers and 2% of all women.

Although, on these measures, women tended to carry a greater burden of care than men, the differences are not great. In the case of 'main' carers, this may be because we did not adequately cover the elements of responsibility discussed earlier. It may be that women are more likely than men to take ultimate responsibility for ensuring that a dependant is adequately cared for but this kind of burden is not easily measured. It may also be that women under-estimate their contribution, as has been found in studies of childcare. A survey of Women's Employment[6] found that one half of all married women considered that childcare was shared equally with their husbands and, even among non-working women, the proportion was 40%. It appeared that non-working women tended to discount the time they spent while their husbands were working! Among the husbands of non-working women, a rather lower proportion, 30%, claimed that the care was shared equally. This study also found that husbands and wives tended to do different tasks, the husbands playing with the children or taking them out and the wives doing the more routine tasks of feeding, dressing, etc. Again there are parallels with the gender differences in the kinds of help carers gave.

5. Future work

There is considerable scope for developing our analysis of the burden of care. In particular, it would be useful to link together the individual measures to provide an overall indicator of burden. Although we have completed our work on the project, the data tapes have been made available to other researchers and one organisation is currently carrying out secondary analysis of the data.

There may also be an opportunity for improving the questions. The Department of Health is interested in monitoring changes over time in the numbers of carers and it is likely that a section on informal care will be included again in the GHS.

References

(1) 'Informal Carers', Hazel Green (ISBN 0 11 691226 X, HMSO 1988, price £3.75).

(2) 'Women and Employment: a lifetime perspective', Jean Martin and Ceridwen Roberts (ISBN 0 11 6910 90 9, HMSO 1984, price £9.50).

Table 1 Percentage of adults who were carers and percentages in some sub-groups of carers, by sex

Persons aged 16 and over — *Great Britain: 1985*

	Men	Women	All adults
Percentage of adults who were:			
Carers	12%	15%	14%
Caring for someone in the same household*	4%	4%	4%
Caring for someone in another private household only	8%	11%	10%
Base = 100%	*8,484*	*9,846*	*18,330*

* *Includes people who were caring for someone in the same household and someone in another private household (63 cases)*

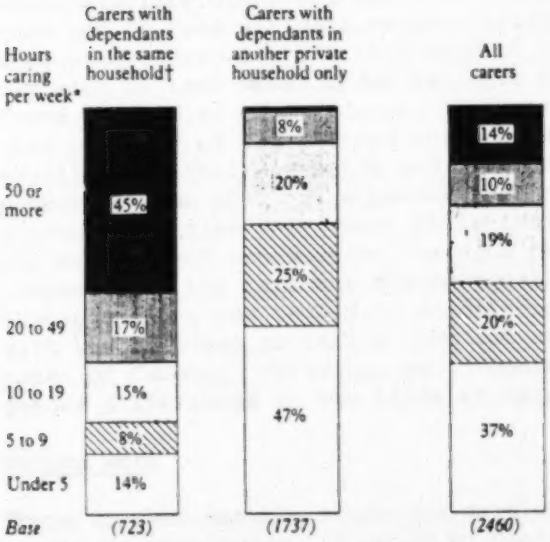
Table 2 Number of hours per week caring for (main)* dependant by whether the dependant lived inside or outside the carer's household and whether main carer

Carers — *Great Britain: 1985*

Number of hours per week devoted to caring	Carers whose (main) dependant lived: in the same household		in another private household		All carers	
	Main carers	Non-main carers	Main carers	Non-main carers	Main carers	Non-main carers
	%	%	%	%	%	%
Under 5	10	30	36	62	26	58
5 to 9	6	18	29	23	20	22
10 to 19	13	28	25	9	20	12
20 to 49	18	12	9	5	12	6
50 or more	53	12	1	Ø	21	2
Base = 100%	*576*	*125*	*947*	*722*	*1,523*	*847*

* *See the footnote to Figure 2*

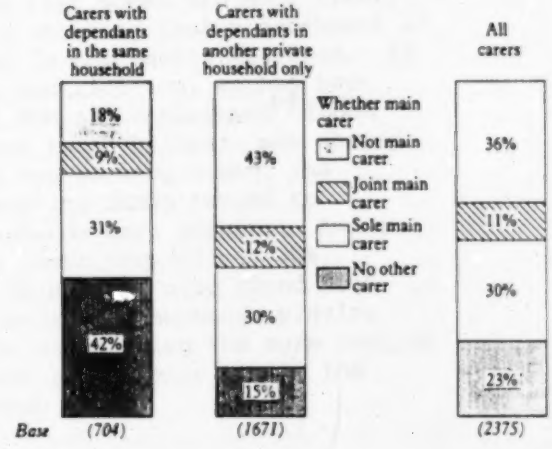
Figure 1 Number of hours caring per week (for all dependants) by whether the dependant lived inside or outside the carer's household; Great Britain, 1985



*Includes time when carer was available in case help was needed

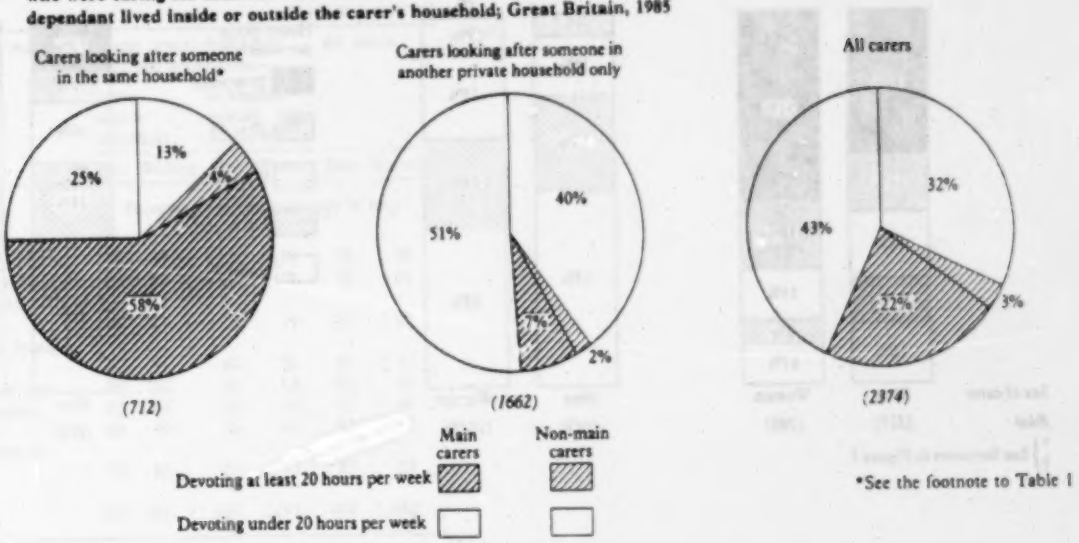
†Includes people caring for someone in the same household and someone in another private household

Figure 2 Carers: whether main carer for (main)* dependant by whether the dependant lived inside or outside the carer's household; Great Britain, 1985



*Where carers were looking after more than one person, information is shown only for the main dependant

Figure 3 Percentages of carers who were the main carers of a dependant and percentages who were caring for someone for at least 20 hours per week, by whether the dependant lived inside or outside the carer's household; Great Britain, 1985



*See the footnote to Table 1

Table 3 Types of help given to (main)* dependant by whether the dependant lived inside or outside the carer's household

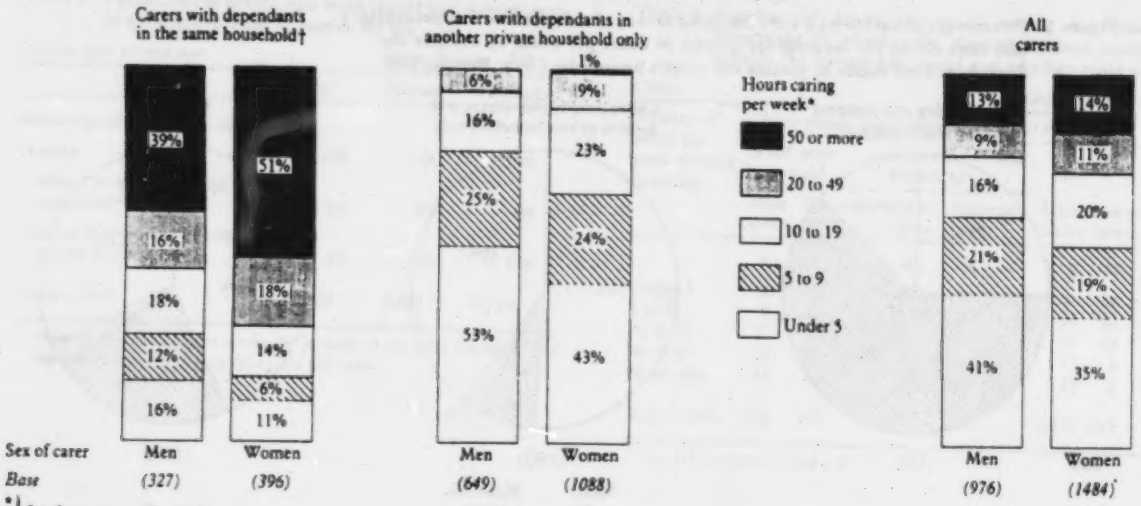
Carers — *Great Britain: 1985*

Help given to (main) dependant	Carers whose (main) dependant lived:		All carers
	in the same household	in another private household	
	Percentage giving each type of help†		
Personal care (eg washing)	53	13	24
Giving medicines	46	13	22
Physical help (eg with walking)	46	12	22
Paperwork or financial matters	47	37	40
Other practical help	81	82	82
Keeping company	64	67	66
Taking out	54	47	49
Keeping an eye on dependant	79	69	72
Base = 100%	*713*	*1,749*	*2,462*

* *See the footnote to Figure 2*

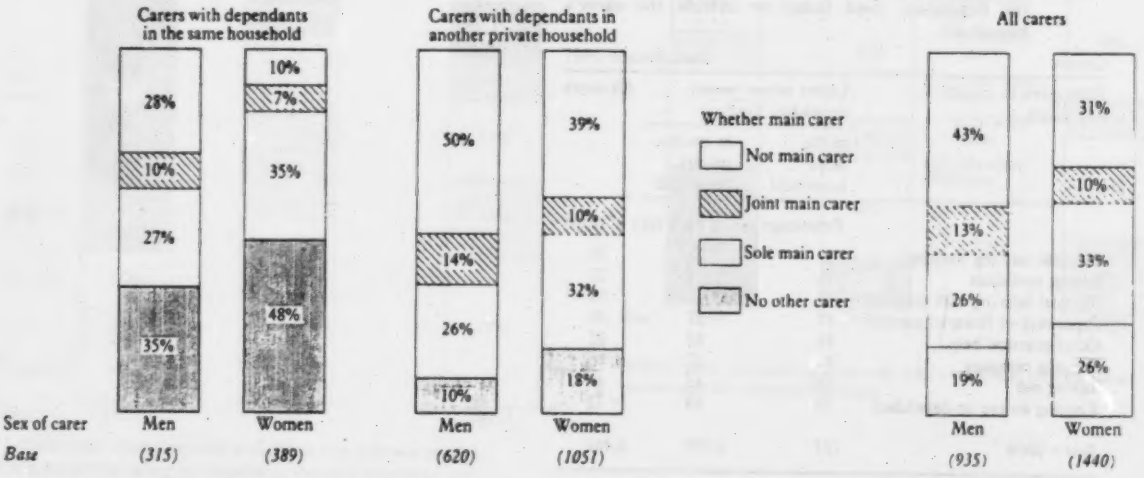
† *Percentages add to more than 100 because some carers gave several types of help.*

Figure 4 Number of hours caring per week (for all dependants) by whether the dependant lived inside or outside the carer's household and sex of carer; Great Britain, 1985



*, † See footnotes to Figure 1

Figure 5 Carers: whether main carer for (main)* dependant by whether the dependant lived inside or outside the carer's household and sex of carer; Great Britain, 1985



*See the footnote to Figure 2

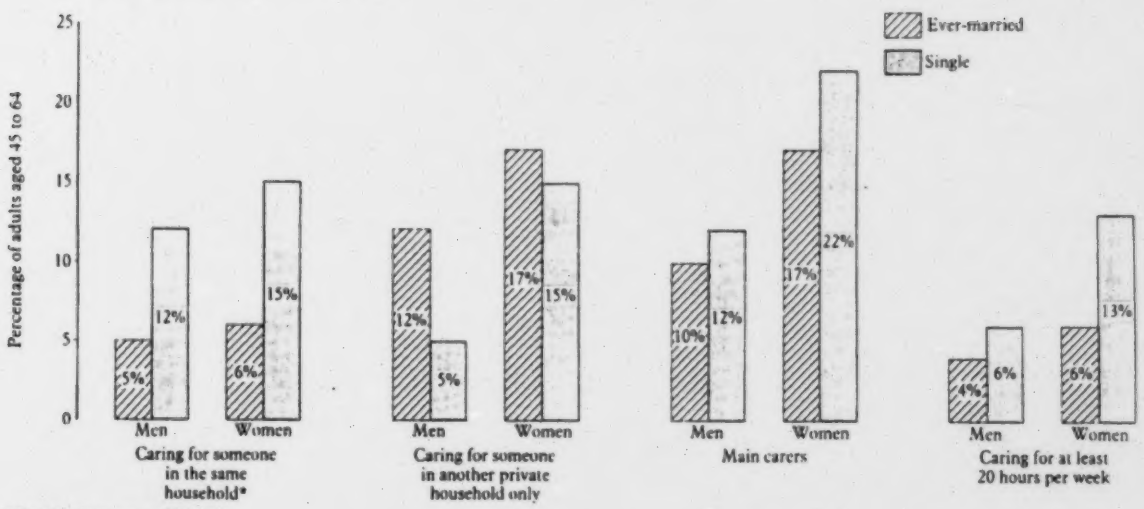
Table 4 Types of help given to (main)* dependant by whether the dependant lived inside or outside the carer's household and sex of carer

Carers — *Great Britain: 1985*

Help given to (main) dependant	Where (main) dependant lived and sex of carer:				All carers	
	in the carer's household		in another private household			
	Men	Women	Men	Women	Men	Women
	Percentages giving each type of help†					
Personal care (eg washing)	43	62	7	16	19	28
Giving medicines	37	53	10	14	19	24
Physical help (eg with walking)	46	46	10	14	22	22
Paperwork or financial matters	42	51	40	36	41	40
Other practical help	82	80	82	82	82	82
Keeping company	63	64	63	69	63	68
Taking out	60	49	50	46	53	47
Keeping an eye on dependant	75	83	63	72	67	75
Base = 100%	*322*	*391*	*658*	*1,091*	*980*	*1,482*

* *See the footnote to Table 2*
† *See the footnote to Table 3*

Figure 6 Percentage of adults aged 45 to 64 in some sub-groups of carers by sex and marital status; Great Britain, 1985



*See the footnote to Table 1